Funding Human Embryonic Stem Cell Research: Science & Scientists in Congress

Jason Owen-Smith Mariana Craciun
University of Michigan

We will lift the current Administration's ban on using federal funding for embryonic stem cells–cells that would have otherwise have been discarded and lost forever–for research that could save lives. We will ensure that our patent laws protect legitimate rights while not stifling innovation and creativity. We will end the Bush Administration's war on science, restore scientific integrity, and return to evidence-based decision-making. -- **2008 Democratic Party Platform**

Taxpayer-funded medical research must be based on sound science, with a focus on both prevention and treatment, and in accordance with the humane ethics of the Hippocratic Oath. In that regard, we call for a major expansion of support for the stem-cell research that now shows amazing promise and offers the greatest hope for scores of diseases — with adult stem cells, umbilical cord blood, and cells reprogrammed into pluripotent stem cells — without the destruction of embryonic human life. We call for a ban on human cloning and a ban on the creation of or experimentation on human embryos for research purposes.
-- **2008 Republican Party Platform**

Rush Limbaugh On the Offensive Against Ad With Michael J. Fox

By David Montgomery
Washington Post Staff Writer
Wednesday, October 25, 2006; Page C01

Possibly worse than making fun of someone's disability is saying that it's imaginary. That is not to mock someone's body, but to challenge a person's guts, integrity, sanity.

To Rush Limbaugh on Monday, Michael J. Fox looked like a faker. actor, who suffers from Parkinson's disease, has done a series litical ads supporting candidates who favor stem cell ch, including Maryland Democrat Ben Cardin, who is against Republican Michael Steele for the Senate seat cated by Paul Sarbanes.

ggeratin

Enlarge This Photo

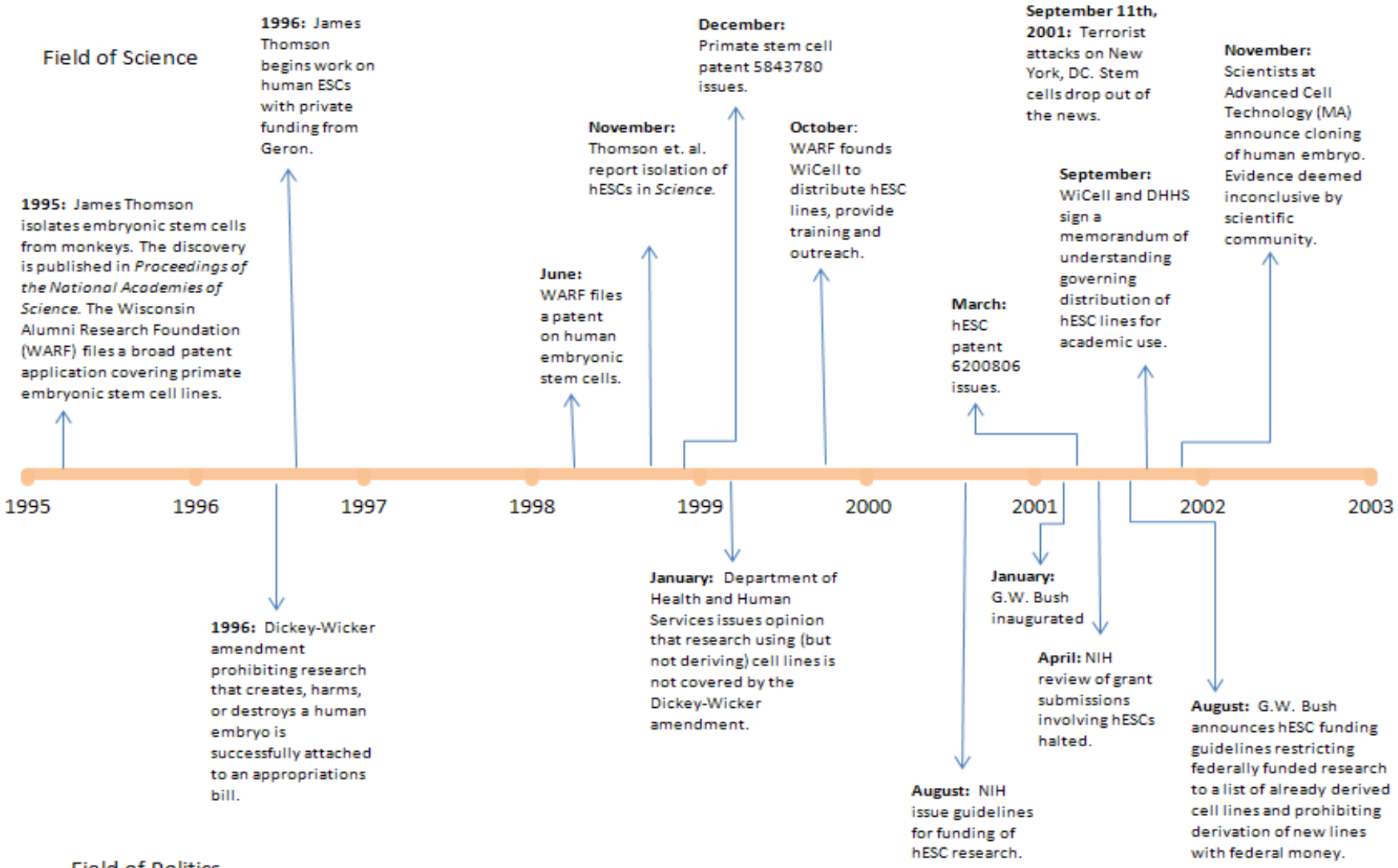
Overview

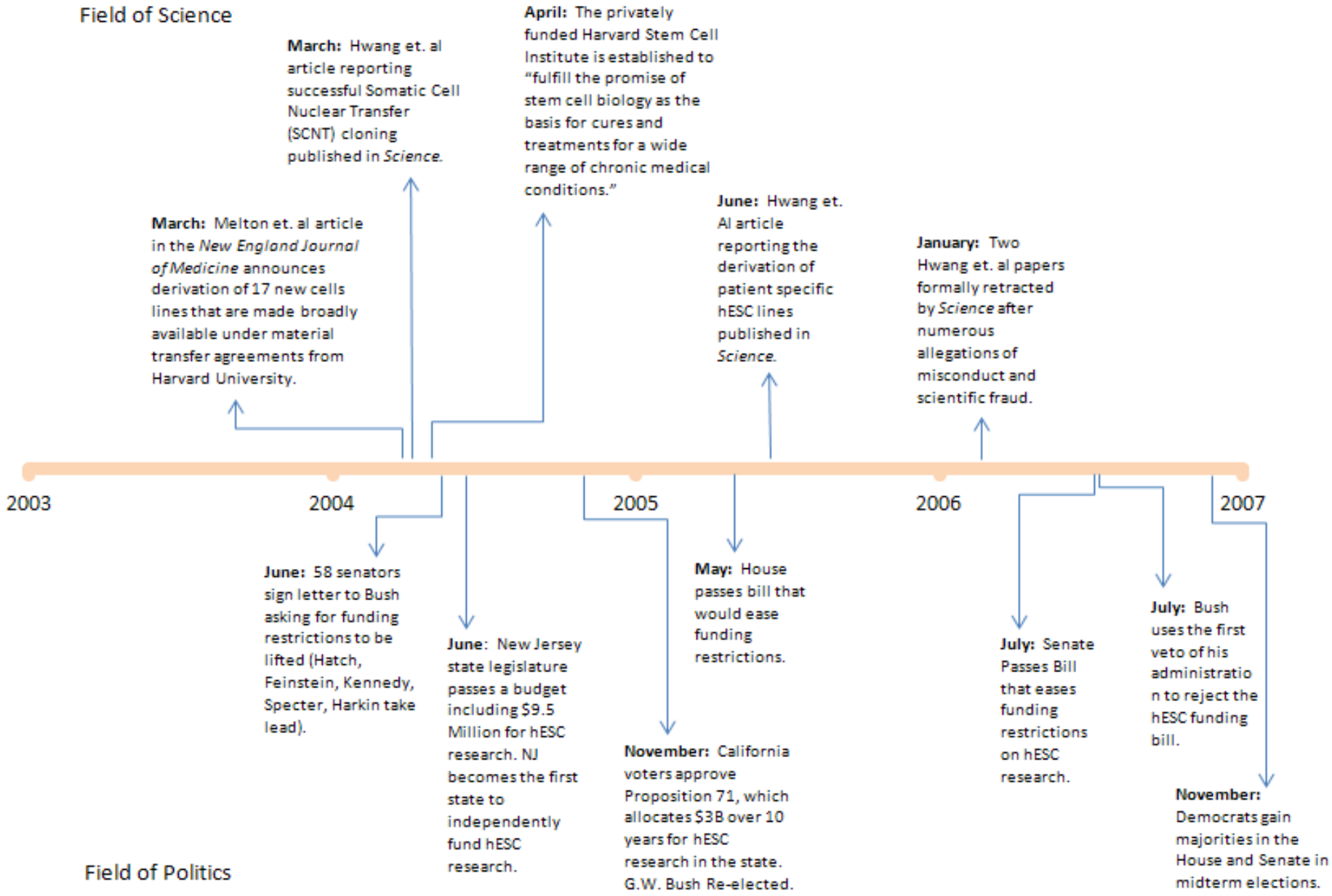
Public debates about controversial issues of science policy can shed light on

1. The social status of science and scientists
2. The tension b/t scientific expertise and democratic decision-making
3. The processes by which discursive fields take shape and change

Our paper undertakes an analysis of congressional hearing testimonies on the issue of whether to fund human embryonic stem cell research (hESC).

1. Describe Data
2. Example Coding
3. Frequencies and Correspondence Analyses
4. Talk through the “status of materials”


Field of Science
1995: James Thomson isolates embryonic stem cells from monkeys. The discovery is published in *Proceedings of the National Academies of Science*. The Wisconsin Alumni Research Foundation (WARF) files a broad patent application covering primate embryonic stem cell lines.
1996: James Thomson begins work on human ESCs with private funding from Geron.
1996: Dickey-Wicker amendment prohibiting research that creates, harms, or destroys a human embryo is successfully attached to an appropriations bill.
June: WARF files a patent on human embryonic stem cells.
November: Thomson et. al. report isolation of hESCs in *Science*.
December: Primate stem cell patent 5843780 issues.
October: WARF founds WiCell to distribute hESC lines, provide training and outreach.
January: Department of Health and Human Services issues opinion that research using (but not deriving) cell lines is not covered by the Dickey-Wicker amendment.
March: hESC patent 6200806 issues.
August: NIH issue guidelines for funding of hESC research.
September 11th, 2001: Terrorist attacks on New York, DC. Stem cells drop out of the news.
January: G.W. Bush inaugurated
April: NIH review of grant submissions involving hESCs halted.
September: WiCell and DHHS sign a memorandum of understanding governing distribution of hESC lines for academic use.
August: G.W. Bush announces hESC funding guidelines restricting federally funded research to a list of already derived cell lines and prohibiting derivation of new lines with federal money.
November: Scientists at Advanced Cell Technology (MA) announce cloning of human embryo. Evidence deemed inconclusive by scientific community.
1995
1996
1997
1998
1999
2000
2001
2002
2003
Field of Politics


Field of Science
March: Hwang et. al article reporting successful Somatic Cell Nuclear Transfer (SCNT) cloning published in Science.
April: The privately funded Harvard Stem Cell Institute is established to "fulfill the promise of stem cell biology as the basis for cures and treatments for a wide range of chronic medical conditions."
March: Melton et. al article in the New England Journal of Medicine announces derivation of 17 new cells lines that are made broadly available under material transfer agreements from Harvard University.
June: Hwang et. Al article reporting the derivation of patient specific hESC lines published in Science.
January: Two Hwang et. al papers formally retracted by Science after numerous allegations of misconduct and scientific fraud.
2003
2004
2005
2006
2007
June: 58 senators sign letter to Bush asking for funding restrictions to be lifted (Hatch, Feinstein, Kennedy, Specter, Harkin take lead).
June: New Jersey state legislature passes a budget including $9.5 Million for hESC research. NJ becomes the first state to independently fund hESC research.
May: House passes bill that would ease funding restrictions.
November: California voters approve Proposition 71, which allocates $3B over 10 years for hESC research in the state. G.W. Bush Re-elected.
July: Senate Passes Bill that eases funding restrictions on hESC research.
July: Bush uses the first veto of his administration to reject the hESC funding bill.
November: Democrats gain majorities in the House and Senate in midterm elections.
Field of Politics

Content coding of 111 prepared testimonies from 19 days of non-legislative congressional hearings related to federal funding for hESC research (c.f Molotch & Boden 1985, Bogen & Lynch 1989).

23 inductively developed thematic codes. Exhaustive sentence level coding.

“Structural” analysis of debate in two time periods 1998-August 2001, September 2001-2006

“Interpretive” analysis of framing efforts and rhetorical conflicts surrounding the “status of the materials”

Table 2. Content Coding Themes, Definitions & Examples

THEME NAME AND NUMBER		EXAMPLE
1. PROGRESS	Scientific and societal advances.	"The development of cell lines that may produce almost every tissue of the human body is an unprecedented scientific breakthrough." (Harold Varmus, December 2nd, 1998)
2. DEMOCRACY/REPRESENTATION	Rule 'by and for' the people, referring specifically to who gets to speak for the people and how.	"Our government will truly serve all the people by showing that it will not promote the destruction of one human being to serve another or the development of treatments that millions of Americans would find it morally abhorrent to use." (Richard Doerflinger, December 2nd, 1998)
3. RESPECT	Giving special regard to an important class of entities (i.e. the law, the public, human life).	"No matter what fate may be planned for the developing human being by others, the government must still make its own moral decision to respect life - it cannot single out certain lives as disposable, or as uniquely fit for harmful research, simply because someone else plans to show disrespect for those lives." (Richard Doerflinger, December 2nd, 1998)
4. LEGALITY	Discussed as the spirit of the law and the letter of the law (the latter connecting to specific policies).	"Currently we do not kill terminally ill patients for their organs, though they will die soon anyway, and Federal law prohibits federally funded researchers from doing any harm to an unborn child slated for abortion, though that child will soon be discarded anyway." (Richard Doerflinger, July 18th, 2001)
5. HUMANITY	Characteristics and inalienable rights of particular organisms that make them human.	"While it is true as a matter of historical fact that all human life has begun at conception it is not true that all conception is capable of becoming human life. Nor will it be true for long that all human life must begin with conception." (Arthur Caplan, December 2nd, 1998)
6. MORALITY	Statements of principle or discomfort relating to human embryonic stem cell research and the broader human condition; this can also refer to moral tradeoffs, i.e. giving up some moral norms, in order to allow human lives to be saved.	"Stem cell research in particular has enormous potential for the effective treatment of human disease. Thus, we believe there is a moral imperative to do it in an ethically validated manner." (Lawrence Goldstein, December 2nd, 1998)
7. POTENTIAL	Possibilities (or lack thereof) related with any aspects of stem cell research (e.g. cures for multiple diseases, potential of embryonic versus adult stem cells).	"It is not too unrealistic to say that this research has the potential to revolutionize the practice of medicine and improve the quality and length of life." (Harold Varmus, December 2nd, 1998)
8. ALTERNATIVE TECHNOLOGIES	Reference to less problematic technical means to achieve the goals of stem cell research.	"Given the seriousness of the current shortage of transplantable cells and tissues, the FDA has demonstrated a willingness to consider a broad array of options including the sourcing of cells and indeed whole organs from animals (xenografts) although these sources also pose unique problems of histocompatibility." (Michael West, December 2nd, 1998)

Table 2. Continued.

THEME NAME AND NUMBER	DEFINITION	EXAMPLE
9. (MIS)INFORMATION	Information existing in the public, political and scientific sphere regarding stem cell research.	"I feel that misinformation is our enemy more than anything else." (Michael West, July 18th, 2001)
10. SOURCES OF KNOWLEDGE	The grounds on which speakers lay claim to truth in the area of stem cell research (from scientific, moral, political and representational points of view); fields but not specific conditions, regime or expertise claims.	"As many scientists, policy makers, religious leaders and the American people have long understood, research that may lead to the elucidation of the secrets of human reproduction and development, the modification of the genetic makeup of future children and their children, the creation of new forms of life and a bounty of therapies that hold out the prospect of a longer and better life raises issues of ethics and social policy that must be discussed and debated publicly." (Arthur Caplan, December 2nd, 1998)
11. EXPERTISE CLAIMS	More specific than sources of knowledge, this refers to the expertise claims made by scientists, ethicists, and others testifying before congress.	"As the head of a not-for-profit group eager to find cures and preventions for the diseases of aging and overall better health and vitality for the elderly, my views on research are dictated by the medical needs of the growing population of older Americans." (Daniel Perry, December 2nd, 1998)
12. OVERSIGHT	Guidelines for undertaking the research; regulatory supervision; implementation of policy.	"We believe that permitting peer-reviewed, Federal funds to be used for this research is our best assurance that the research will be of the highest quality and benefit and performed with proper ethical oversight and public input." (Lawrence Goldstein, April 26th, 2000)
13. SCIENTIFIC ETHICS	The rules/principles that science/scientists need to consider with regard to stem cell research; specifically, the ways in which regulations are interpreted and followed in practice.	"Let me describe the process that we have planned to ensure that any research involving human pluripotent stem cells is appropriately and carefully conducted." (Harold Varmus, January 26th, 1999)
14. POLICY	A plan decided on by the government and administrative body with regards to stem cell research.	"A world without diabetes for all the children and adults who currently suffer from its devastating impact continues to be our goal, and we urge you to ensure that federal policies allow this research to continue to speed our path to cure this disease." (Doug Melton, January 12th, 1999)
15. STATUS OF BIOLOGICAL MATERIALS	Explicit statements regarding the biological materials used in the research (e.g. embryos, cloned embryos, stem cells, stem cell lines); specifically denoting their status as human beings, as well as their biological properties, purity and legality.	"Human ES cell lines are not the equivalent of an intact human embryo. If a clump of ES cells was transferred to a woman's uterus, the ES cells would not implant and would not form a viable fetus." (James Thomson, December 2nd, 1998)
16. DESTRUCTION	Referring specifically to the destruction of human embryos for the purposes of advancing stem cell research.	"Instead, as the National Bioethics Advisory Commission has already observed, avenues should not be explored for creating stem cell lines without creating or destroying human embryos." (Richard Doerflinger, December 2nd, 1998)

Table 2. Continued.

THEME NAME AND NUMBER	DEFINITION	EXAMPLE
17. SLIPPERY SLOPE	Actions or events leading inevitably to others with unintended consequences – it signifies both the line one does not cross and the 'downhill' movement that follows as an inevitable result of crossing that line.	"The utilitarian ethical stance of promoting the greatest good could lead to a new eugenics and the sacrifice of the vulnerable to relieve the pain and suffering and extend the life of the living." (Frank Young, November 4th, 1999)
18. TRADEOFF	Giving up something in return for something else.	"Our society is quite familiar with the concept of tradeoffs. Americans recognize few moral absolutes and in the area of stem cell research where the tradeoffs frequently involve the possibility of harm to potential persons versus the reality of harm to real flesh and blood persons it is hard not to use some of these principles to guide prudent choices, albeit tragic ones." (Arthur Caplan, December 2nd, 1998)
19. PUBLIC SECTOR	Funding by the federal government through NIH; research done at public universities; publications.	"How soon such therapies will be developed will depend on whether there is public support of research in this area." (James Thomson, December 2nd, 1998.)
20. PRIVATE SECTOR	Funding by private companies; specific references to the market and commercial gains; intellectual property.	"When research is funded entirely by the private sector, the government has no license, and it is strictly a private matter whether, and under what terms, new intellectual property is made available to others for commercial or research purposes." (Maria Freire, December 2nd, 1998)
21. SCIENCE HAS THE ANSWERS	Science – through the development of knowledge – can provide us with solutions not only to medical problems but also moral challenges.	"Not only are they suffering, but their families and care givers are suffering too, and hoping that scientists will find cures for these devastating diseases and other conditions while there is still time." (Daniel Perry, December 2nd, 1998)
22. DISEASE/CURE	Specific references to the actual problems and potential benefits that stem cell research could address, afflictions or patient populations.	"The long range benefit of this kind of research is not the unlikely possibility of greatly extended lifetimes, but the plausible use of this technology to restore damaged tissues, using self-renewing, pluripotent human cells to treat blindness, coronary artery damage, diabetes and other diseases." (Daniel Perry, December 2nd, 1998)
23. ACCESS TO/AVAILABILITY OF RESEARCH MATERIALS	Who has access to cell lines, usually in combination with how this is limited or enhanced by sources of funding	"Concerns have also been raised regarding the licensing of technology in the biotechnology area, specifically in the context of the availability or research tools." (Q. Todd Dickinson, January 12th, 1999)

Coding Examples

The NIH Panel recognized the therapeutic promise of human embryo research while recognizing that the human embryo warrants serious moral consideration as a developing form of human life. (James Thomson, University of Wisconsin, 12-02-1998)

Coded

Expertise claims

Potential

Status of the Materials

Morality

None of the 22 stem cell lines approved for use by the NIH carry a gene defect for these or other genetic diseases such as cystic fibrosis and Huntington's disease. (John Gearhart, Johns Hopkins University, 06-08-2005)

Coded

Progress

Science has the Answers

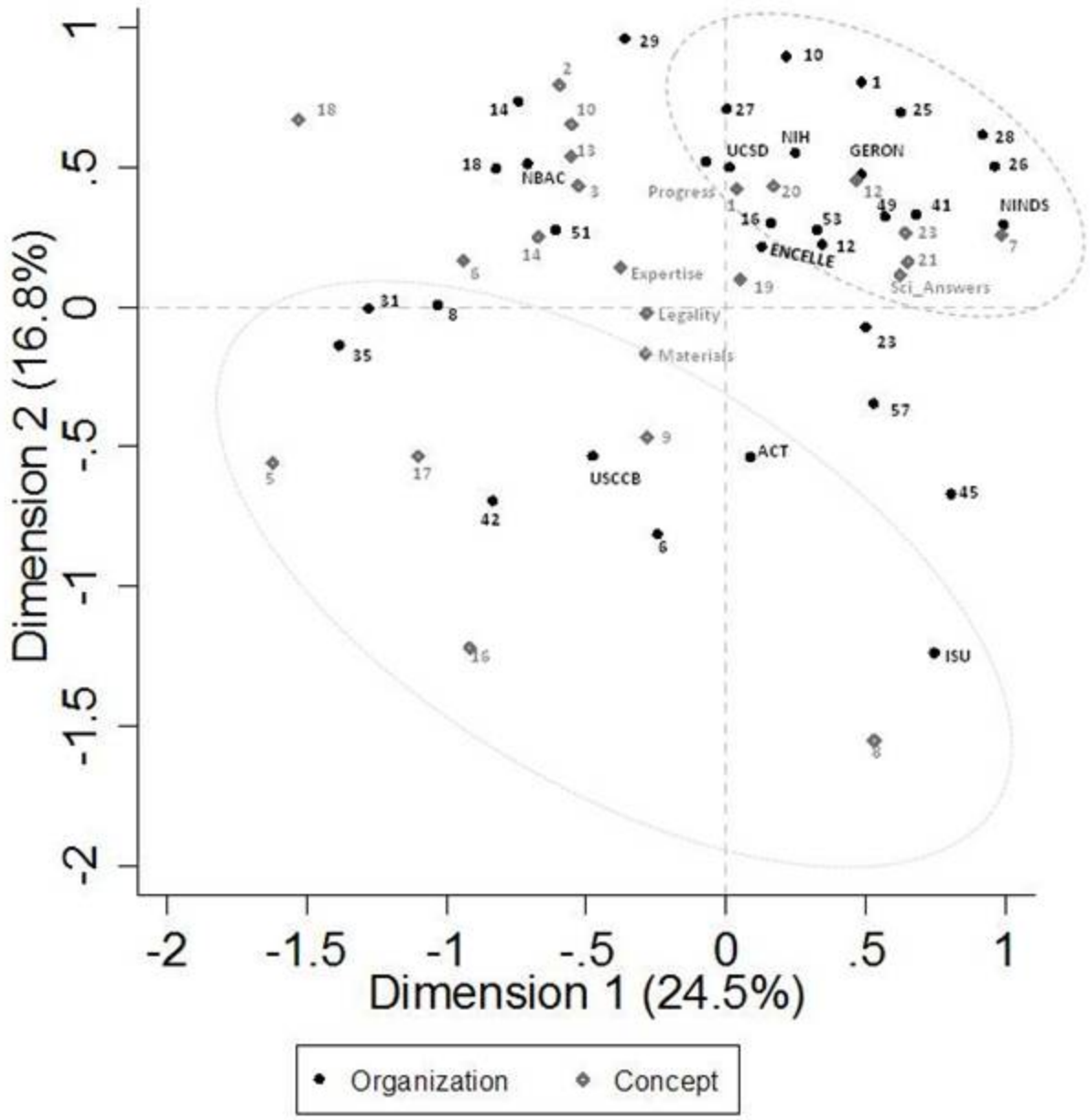
Disease/Cure

Status of the Materials

Table 3. Concept Frequency by Time Period.

	All Years			P1: 1998-08/2001			P2: 09/2001-2005		
Rank	**Concept**	**Count**	**%**	**Concept**	**Count**	**%**	**Concept**	**Count**	**%**
1	Progress	894	8.99%	**Status_Materials**	**626**	**8.96%**	Progress	345	11.66%
2	Science_Answers	865	8.70%	Expertise_Claims	567	8.11%	Disease_Cure	335	11.33%
3	Disease_Cure	863	8.68%	Legality	551	7.88%	Science_Answers	322	10.89%
4	Public_Sector	812	8.16%	Progress	549	7.86%	Public_Sector	313	10.58%
5	Expertise_Claims	772	7.76%	Science_Answers	543	7.77%	Expertise_Claims	205	6.93%
6	Status_Materials	745	7.49%	Potential	532	7.61%	Potential	193	6.52%
7	Potential	725	7.29%	Disease_Cure	528	7.55%	Alternative_Techs	172	5.81%
8	Legality	677	6.81%	Public_Sector	499	7.14%	Sci_Ethics	137	4.63%
9	Alternative_Techs	664	6.68%	Alternative_Techs	492	7.04%	Access_Avail	133	4.50%
10	Private_Sector	512	5.15%	Morality	413	5.91%	Legality	126	4.26%
11	Morality	490	4.93%	Private_Sector	390	5.58%	Private_Sector	122	4.12%
12	Oversight	286	2.88%	Oversight	224	3.21%	**Status_Materials**	**119**	**4.02%**
13	Sci_Ethics	284	2.86%	Democracy/Representation	212	3.03%	Policy	113	3.82%
14	Democracy/Representation	240	2.41%	Destruction	170	2.43%	Morality	77	2.60%
15	Destruction	204	2.05%	Humanity	160	2.29%	Oversight	62	2.10%
16	Access_Avail	203	2.04%	Sci_Ethics	147	2.10%	Knowledge_Sources	37	1.25%
17	Humanity	189	1.90%	Knowledge_Sources	103	1.47%	Destruction	34	1.15%
18	Policy	186	1.87%	Policy	73	1.04%	Humanity	29	0.98%
19	Knowledge_Sources	140	1.41%	Access_Avail	70	1.00%	Democracy/Representation	28	0.95%
20	Respect	88	0.88%	Respect	60	0.86%	Respect	28	0.95%
21	Mis(information)	83	0.83%	Mis(information)	58	0.83%	Mis(information)	25	0.85%
22	Tradeoff	13	0.13%	Slippery_Slope	11	0.16%	Tradeoff	2	0.07%
23	Slippery_Slope	12	0.12%	Tradeoff	11	0.16%	Slippery_Slope	1	0.03%
	Total	**9,947**		**Total**	**6,989**		**Total**	**2,958**	

Figure 2. Correspondence Analysis Biplot: 1998-Aug. 2001

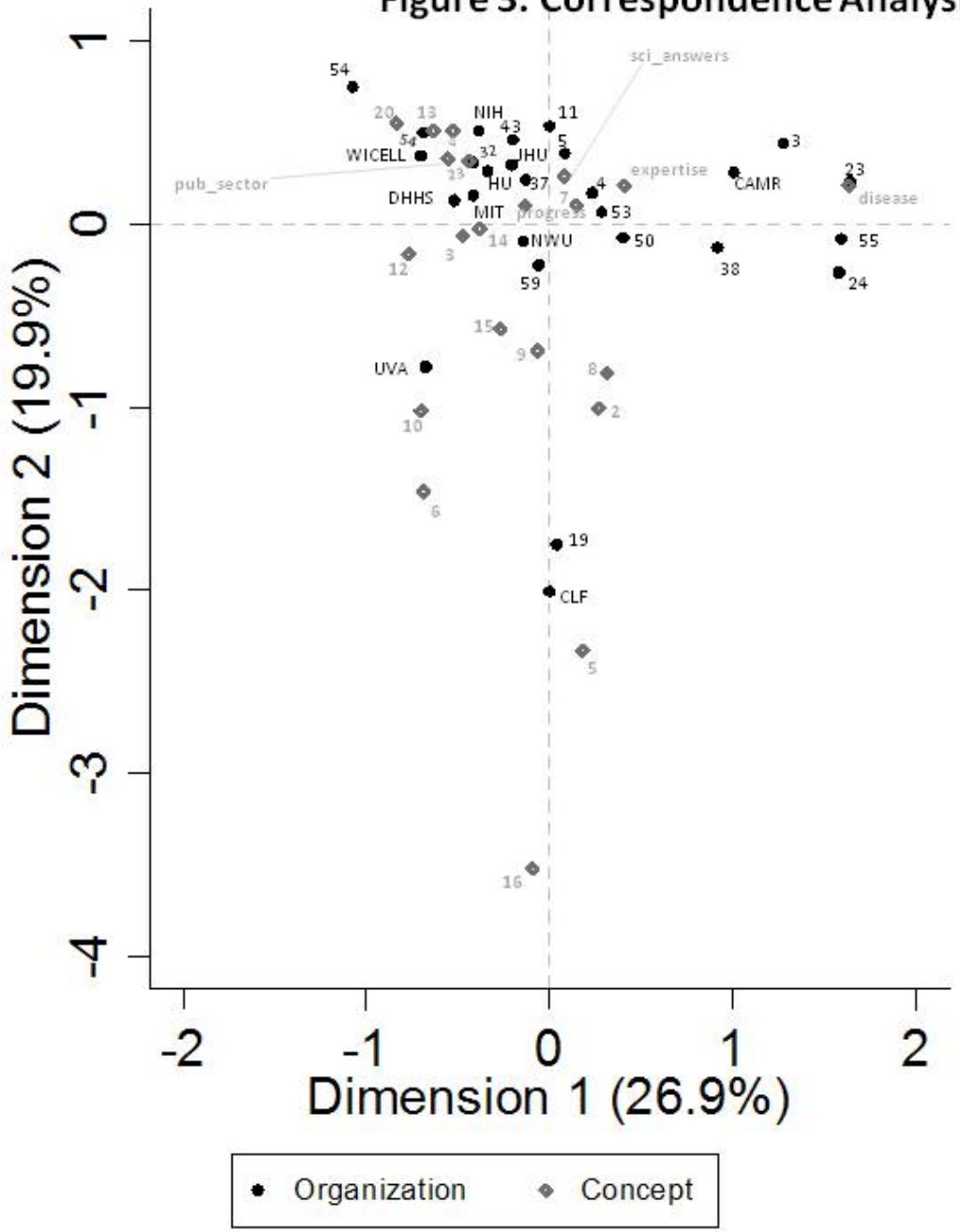


Period 1 Organization Codes	
AAR	1
CAFS	6
CBPP	8
CRPF	10
Columbia	12
DIPP	14
Eastern_VA	16
JDA	25
JDF	26
JHU	28
JDRFI	28
JRM	29
MIT	30
Mayo	31
NBAC	33
NBAC	33
NCOPD	35
PAN	41
RH_Lutheran	42
Tulane	45
UCSD	46
UCSD	46
U_Iowa	49
U_Wisc	53
Yale	57

Concept_Codes	
1	Progress
2	Democracy
3	Respect
4	Legality
5	Humanity
6	Morality
7	Potential
8	Alt_Techs
9	Mis(information)
10	Knowledge_Source
11	Expertise
12	Oversight
13	Sci_Ethics
14	Policy
15	Status_Materials
16	Destruction
17	Slippery_Slope
18	Tradeoff
19	Pub_Sector
20	Priv_Sector
21	Sci_Answer
22	Disease_Cure
23	Access_Avail

Notes: The 10 most common organizations and 5 most common concepts are labeled. See Table 4 for a key to organizational abbreviations. Organizations are capitalized, concepts are labeled in lower-case. Only organizations marked with codes are included in key.

Figure 3. Correspondence Analysis Biplot: Sep. 2001-2006



Period 2 Organization Codes	
ASCB	3
Alpha_1	4
BIO	5
Georgetown	19
Indiv.	23
JCCC	24
Monash_U	32
ASCB	33
NINDS	37
NMRC	38
NRC	39
Technion	43
U_Minn	50
U_Pitt	52
U_Wisc	53
Cambridge	54
Wash_U	55

Concept_Codes	
1	Progress
2	Democracy
3	Respect
4	Legality
5	Humanity
6	Morality
7	Potential
8	Alt_Techs
9	Mis(information)
10	Knowledge_Source
11	Expertise
12	Oversight
13	Sci_Ethics
14	Policy
15	Status_Materials
16	Destruction
17	Slippery_Slope
18	Tradeoff
19	Pub_Sector
20	Priv_Sector
21	Sci_Answer
22	Disease_Cure
23	Access_Avail

Notes: The 10 most common organizations and 5 most common concepts are labeled. See Table 4 for a key to organizational abbreviations. Organizations are capitalized, concepts are labeled in lower-case.

Period 1: Is the embryo human

“We do not kill terminally ill patients for their organs, although they will die soon anyway, or even harvest vital organs from death row prisoners, although they will be put to death soon anyway. Federal law prohibits federally funded researchers from doing any harm to an unborn child slated for abortion, though that child will soon be discarded anyway (see 42 USC Sec. 289g). If people's value depends entirely on the extent to which other people “want” them, they have no inherent value at all.” (Richard Doerflinger, National Conference of Catholic Bishops, 07-18-2001

There are some who would still object that these frozen embryos are … potential persons. But that claim does not square with the facts. If no woman is willing to have the embryos placed inside her bodies [sic], if clinics are reluctant to use embryos that have been stored for long periods of time because their potential to become babies is diminished or if couples do not want anyone else using their embryos then their potential for becoming persons is zero. (Arthur Caplan, University of Pensylvania Center for Bioethics, 12-02-1998)

Period 2: Are fundable cell lines sufficient for scientific/therapeutic goals

Scientific research and progress since 2001 have revealed the limitations of the eligible lines, and shown us the extent to which these existing lines are not adequate to realize the full potential of embryonic stem cell research. The 22 lines now eligible for federally funded research are contaminated with animal cells, lack genetic diversity, are not disease-specific, and are not adequate for researchers to apply to a wide variety of diseases. Limiting researchers to work only on with those lines with federal funding ignores scientific advancements and places unnecessary obstacles in the way of possible therapies and treatments. (John Gearhart, Johns Hopkins University 06-08-2005)

Conclusions/Implications

- Science Policy Debates offer an important arena for studies in the "new political sociology of science" (Frickel & Moore 2006)

- Conflicting 'logics of justification' and 'civil epistemologies' make specific policy debates about much more than their narrow questions

- Debates are structured and strategic – discursive space of debate shifts with
  1. Scientific Discoveries/Developments
  2. Policy Changes (Bush, Prop. 71)
  3. Strategic Framing Efforts

- Scientists engagements shift language (and direction?) of scientific justification